

The Right to Refuse Treatment: A Model Act

BY THE
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Abstract: Although the right to refuse medical treatment is universally recognized as a fundamental principle of liberty, this right is not always honored. A refusal can be thwarted either because a patient is unable to competently communicate or because providers insist on continuing treatment. To help enhance the patient's right to refuse treatment, many states have enacted so-called "living will" or "natural death" statutes. We believe the time

has come to move beyond these current legislative models, and we therefore propose a Model Act that clearly enunciates an individual's right to refuse treatment, does not limit its exercise to the terminally ill or to heroic measures, and provides a mechanism by which individuals can set forth their wishes in advance and designate another person to enforce them. (*Am J Public Health* 1983; 73:918-921.)

Introduction

The most important right that patients possess is the right of self-determination, the right to make the ultimate decision concerning what will or will not be done to their bodies.¹ This right, embodied in the informed consent doctrine, has a critical and essential corollary: the right to refuse treatment.² Unless the right to refuse treatment is honored, the right of self-determination degenerates into a "right" to agree with one's physician.

Courts have recently declared that both the common law³ and the United States Constitution⁴ protect an individual's right to refuse medical treatment. These decisions might be seen as arguments against legislation that would reaffirm and enhance this right since such legislation might be viewed as either unnecessary or undesirable and confusing. On the other hand, cases continue to recur in which individuals are treated despite their competent objections or withdrawal of consent.^{5,6} And although courts universally recognize the patient's right to refuse treatment, they have differed in their enunciation of the proper standards to be followed in implementing this right.^{3,4,7} We believe the centrality of the right to refuse treatment makes its periodic reaffirmation appropriate, and a clear articulation of its applicability in particular contexts is a proper subject for legislation.

Living Will and Natural Death Statutes

To help promote the right of self-determination by preventing unwanted heroic medical interventions, many commentators have proposed, and 12 states and the District of Columbia have adopted, so-called "living will" or "natural death" statutes.⁸ The primary purpose of these statutes is to provide competent individuals with a mechanism to set forth in a document, called a "living will," what they do and

do not want done to them in case they become mentally incompetent and require medical intervention to keep them alive.

The rationale is that, with the advent of more effective medical technology, patients may have their lives prolonged painfully, expensively, fruitlessly, and against their wills. By signing a prior statement, the patient hopes to avoid a technological imperative which commands that that which can be done, must be done, and instead keep some control over his or her medical treatment.

Although specific provisions of these statutes vary, a typical statute allows patients to direct the withholding or withdrawal of medical treatment in the event the patient becomes terminally ill. Most current "living will" statutes basically permit physicians to honor a terminally ill patient's directive not to be treated if the physician agrees that treatment is not indicated. This, of course, can be done in the absence of any statute^{2,9-11}; and the current statutes do not so much enhance patients' rights as they enhance provider privileges (i.e., physicians typically are granted immunity if they follow a patient's directive, but are not required to follow it if they do not want to).¹²⁻²⁰

Previous Model Acts

Model statutes suggested by other commentators have been of three basic kinds: 1) syntheses of the best features of existing legislation and proposals²¹⁻²³; 2) proposals to extend the right to refuse treatment to nonterminally ill patients²⁴; and 3) proposals to permit the individual to designate another person to make the treatment decisions when the individual is unable to make them.^{25,26} We believe all of these efforts are laudatory, and have attempted to incorporate in our own model the best of each current proposal. However, we also believe it is time to move beyond the limitations of "living will" and "natural death" legislation, and propose a model that incorporates all the features necessary in what might be considered "second generation" legislation. Such legislation:

- should not be restricted to the terminally ill, but should apply to all competent adults and mature minors;
- should not limit the types of treatment an individual can refuse (e.g., to "extraordinary" treatment) but should apply to all medical interventions;

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- should permit individuals to designate another person to act on their behalf and set forth the criteria under which the designated person is to make decisions;
- should require health care providers to follow the patient's wishes and provide sanctions for those who do not do so;
- should require health care providers to continue to provide palliative care to patients who refuse other interventions.

The Model Legislation

The specific provisions of our proposal are set forth in the Appendix to this article. Many of the sections are self-explanatory, but some merit additional comment. No specific form or document is included because we believe the individual's wishes will be more likely to be set forth if their own words are used.

It should be stressed initially that the right being reaffirmed is the right to refuse treatment implicit in any meaningful concept of individual liberty. Living will statutes, on the other hand, usually rely on a vaguely articulated "right to die" which has no legal pedigree. We include both adults and mature minors in the purview of the Act because we believe minors who understand the nature and consequences of their actions should not be forced to undergo medical treatment against their will.

Competence

The definitions seek to clarify the scope of the right by including all "competent" individuals who can understand the nature and consequences of their decisions. Thus while mature minors and previously competent individuals are included, individuals who have never been competent or who did not express their wishes while competent are not within the scope of the proposal. The competent person's understanding must be attested to by two adult witnesses at the time a written declaration is executed, or be determined at the time of an oral refusal. While the Act's definition of competence is consistent with the law of most states on this subject, hospitals may wish to develop objective criteria, procedures, and documentation requirements to assess competency accurately.

The competence standard used is a functional one, based on the individual's ability to give informed consent. It rejects any notion that a patient's decision must be consistent with the "medically rational choice" as defined by the physician. Competence is *the* crucial issue, since a lack of competence, or even the questioning of an individual's competence, deprives the individual of the power to make treatment decisions.

For example, in *Lane v. Candura*, a 77-year-old woman refused to permit amputation of her gangrenous leg. Her physician believed that this decision, which would lead to her death, was medically irrational, and that Mrs. Candura was incompetent.²⁷ As is often the case, Mrs. Candura's competence was not questioned at any time when she agreed to undergo recommended surgical procedures. The court noted that Candura's occasional fluctuations in mental lucidity did not affect her basic ability to understand what the doctor wanted to do and what would happen if he didn't: she knew that the doctor wanted to amputate her leg, and that he believed she would otherwise die. The court also clarified that the competent patient's decision must be respected even

when, as in this case, physicians or others consider it unfortunate, medically irrational, or misguided. Using these principles, the court refused to appoint a guardian for Mrs. Candura since she had exhibited a reasonable appreciation of the issues surrounding the treatment refusal. Other courts have validated a competence definition substantially identical to the one used in this Act.^{2,28-31}

The proposed Act aims at protecting the autonomy of not only terminally ill patients, but those who are not terminally ill as well. If we do not raise our sensitivity regarding respect for the nonterminal patient's right to autonomy, it is extremely unlikely that the rights of terminal patients will be respected. The Act also applies to patients like Karen Ann Quinlan who, while in a hopeless, persistent vegetative state, do not suffer from an underlying, terminal illness.

Designating a Proxy

The President's Commission for the Study of Ethical Problems in Medicine has recently noted that "by combining a proxy directive with specific instructions, an individual could control both the content and the process of decision-making about care in case of incapacity."³² Concern for Dying's Act incorporates this suggestion by permitting the declarant to both define what interventions are refused, and to name an authorized individual to make decisions consistent with the declarant's desires as expressed in the declaration. Thirty-seven states currently have durable power of attorney laws that arguably permit such a designation, provided that the individual gives specific authorization regarding medical treatment. However, these statutes were passed long before living wills became an issue, and although we believe courts should honor medical decisions made by a proxy named under a durable power of attorney statute, there have been no reported cases on this issue to date.^{32,33}

There is no time limit to the validity of declarations, just as there is no time limit on ordinary wills or on donations made under Uniform Anatomical Gift Acts. The primary protection regarding the authenticity of the wishes of a person is the requirement for two witnesses to certify that they believe the person understood what he was signing and did it voluntarily. We have not restricted the individuals who can be either witnesses or authorized persons (e.g., the attending physician or relatives who might benefit under a will are not excluded because we think this unnecessarily implies bad faith on the part of categories of individuals and unnecessarily restricts the autonomy of a person to choose his own proxy and witnesses). Further, criminal penalties exist for falsification and forgery, and, if a physician or relative wants to harm the declarant, there are much easier ways to do it than by utilizing this mechanism. A second protection for the declarant is that revocation of a declaration is made easy. But the intent to revoke must be specific. Merely signing a blanket hospital admissions form that "consents" to whatever treatment physicians at the hospital wish to render is insufficient indication of revocation of a declaration.

Responsibility of Providers

The Model Act further clarifies that refusal of treatment does not terminate the physician-patient relationship, and that a physician who declines to follow the patient's wishes must transfer the patient to a physician who will. The Act

recognizes that some providers may have different belief or value systems from the people they care for as patients, and attempts to establish a realistic procedure which allows the ethical views of both parties to be respected. However, the Act also recognizes that the patient is most immediately affected by failure to carry out a treatment-refusal decision, since the patient's own future and quality of life are at stake. Consequently, when a patient's directive and provider's views differ, the patient's directive must prevail over the physician's views on the rare occasions where transfer is impossible.

Providers who follow the procedures outlined in this Act are relieved of liability pursuant to any civil, criminal, or administrative action. However, providers who abandon their patients or refuse to comply with valid declarations are subject to sanctions. They may face civil actions including charges of negligence and battery. Administrative sanctions may include license revocation, suspension, or other disciplinary action by the state board of professional registration.

Other sections of the Act make it clear that this method of refusing treatment is not exclusive, but in addition to any other methods recognized by law; that the refusal of treatment is not suicide; that a treatment refusal does not affect any insurance policy; and that regardless of refusals, palliative care must be given unless specifically refused by the patient himself.

Summary

In summary, this model Right to Refuse Treatment Act clearly enunciates the competent person's right to refuse treatment, does not limit the exercise of this right to terminally ill patients or to extraordinary or heroic measures, and provides a mechanism by which a competent person can declare his or her intentions concerning treatment in the event of future incompetence, and can name another person to enforce this declaration.

The Act is designed to promote autonomy and respect for persons, by enhancing the individual's right to accept or reject medical treatments recommended by health care providers. It protects all competent persons, and incompetent persons who executed a declaration while they were competent. It provides that individuals may execute a written, signed declaration setting forth their intentions on treatment and refusal decisions and permits them to designate authorized individuals to make treatment decisions on their behalf, should they become incompetent in the future. The Act expresses, upholds, and clarifies recognized patient rights to autonomy and inviolability, recognition of which accords with the ethics of the medical profession; shields complying physicians, witnesses, and authorized persons acting in good faith, from liability; and provides sanctions for those who violate its provisions.

It has been almost three-quarters of a century since Judge Benjamin Cardozo wrote, regarding medical care that, "Every human being of adult years has a right to determine what shall be done with his own body."³⁴ Today's medical care would be incomprehensible to a physician practicing when these words were written. Nonetheless, medicine's success in radically improving its ability to prolong life has made the right of self-determination an even more vital principle. By proposing this Act, the Legal Advisors of Concern for Dying reaffirm the right to self-determination in the hope that the discussion fostered will enhance the liberty of all citizens.

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APPENDIX RIGHT TO REFUSE TREATMENT ACT

Section 1. Definitions

"Competent person" shall mean an individual who is able to understand and appreciate the nature and consequences of a decision to accept or refuse treatment.

"Declaration" shall mean a written statement executed according to the provisions of this Act which sets forth the declarant's intentions with respect to medical procedures, treatment or nontreatment, and may include the declarant's intentions concerning palliative care.

"Declarant" shall mean an individual who executes a declaration under the provisions of this Act.

"Health care provider" shall mean a person, facility or institution licensed or authorized to provide health care.

"Incompetent person" shall mean a person who is unable to understand and appreciate the nature and consequences of a decision to accept or refuse treatment.

"Medical procedure or treatment" shall mean any action taken by a physician or health care provider designed to diagnose, assess, or treat a disease, illness, or injury. These include, but are not limited to, surgery, drugs, transfusions, mechanical ventilation, dialysis, resuscitation, artificial feeding, and any other medical act designed for diagnosis, assessment or treatment.

"Palliative care" shall mean any measure taken by a physician or health care provider designed primarily to maintain the patient's comfort. These include, but are not limited to, sedatives and pain-killing drugs; non-artificial, oral feeding; suction; hydration; and hygienic care.

"Physician" shall mean any physician responsible for the declarant's care.

Section 2.

A competent person has the right to refuse any medical procedure or treatment, and any palliative care measure.

Section 3.

A competent person may execute a declaration directing the withholding or withdrawal of any medical procedure or treatment or any palliative care measure, which is in use or may be used in the future in the person's medical care or treatment, even if continuance of the medical procedure or treatment could prevent or postpone the person's death from being caused by the person's disease, illness or injury. The declaration shall be in writing, dated and signed by the declarant in the presence of two adult witnesses. The two witnesses must sign the declaration, and by their signatures indicate they believe the declarant's execution of the declaration was understanding and voluntary.

Section 4.

If a person is unable to sign a declaration due to a physical impairment, the person may execute a declaration by communicating agreement after the declaration has been read to the person in the presence of the two adult witnesses. The two witnesses must sign the declaration, and by their signatures indicate the person is physically impaired so as to be unable to sign the declaration, that the person understands the declaration's terms, and that the person voluntarily agrees to the terms of the declaration.

Section 5.

A declarant shall have the right to appoint in the declaration a person authorized to order the administration, withholding, or withdrawal of medical procedures and treatment in the event that the declarant becomes incompetent. A person so authorized shall have the power to enforce the provisions of the declaration and shall be bound to exercise this authority consistent with the declaration and the authorized person's best judgment as to the actual desires and preferences of the declarant. No palliative care measure may be withheld by an authorized person unless explicitly provided for in the declaration. Physicians and health care providers caring for incompetent declarants shall provide such authorized persons all medical information which would be available to the declarant if the declarant were competent.

Section 6.

Any declarant may revoke a declaration by destroying or defacing it, executing a written revocation, making an oral revocation, or by any other act evidencing the declarant's specific intent to revoke the declaration.

Section 7.

A competent person who orders the withholding or withdrawal of treatment shall receive appropriate palliative care unless it is expressly stated by the person orally or through a declaration that the person refuses palliative care.

Section 8.

This act shall not impair or supersede a person's legal right to direct the withholding or withdrawal of medical treatment or procedures in any other manner recognized by law.

Section 9.

No person shall require anyone to execute a declaration as a condition of enrollment, continuation, or receipt of benefits for disability, life, health or any other type of insurance. The withdrawal or withholding of medical procedures or treatment pursuant to the provisions of this Act shall not affect the validity of any insurance policy, and shall not constitute suicide.

Section 10.

This Act shall create no presumption concerning the intention of a person who has failed to execute a declaration. The fact that a person has failed to execute a declaration shall not constitute evidence of that person's intent concerning treatment or nontreatment.

Section 11.

A declaration made pursuant to this Act, an oral refusal by a person, or a refusal of medical procedures or treatment through an authorized person, shall be binding on all physicians and health care providers caring for the declarant.

Section 12.

A physician who fails to comply with a written or oral declaration and to make necessary arrangements to transfer the declarant to another physician who will effectuate the declaration shall be subject to civil liability and professional disciplinary action, including license revocation or suspension. When acting in good faith to effectuate the terms of a declaration or when following the direction of an authorized person appointed in a declaration under Section 5, no physician or health care provider shall be liable in any civil, criminal, or administrative action for withholding or withdrawing any medical procedure, treatment, or palliative care measure. When acting in good faith, no witness to a declaration, or person authorized to make treatment decisions under Section 5, shall be liable in any civil, criminal, or administrative action.

Section 13.

A person found guilty of willfully concealing a declaration, or falsifying or forging a revocation of a declaration, shall be subject to criminal prosecution for a misdemeanor [the class or type of misdemeanor is left to the determination of individual state legislatures].

Section 14.

Any person who falsifies or forges a declaration, or who willfully conceals or withholds information concerning the revocation of a declaration, with the intent to cause a withholding or withdrawal of life-sustaining procedures from a person, and who thereby causes life-sustaining procedures to be withheld or withdrawn and death to be hastened, shall be subject to criminal prosecution for a felony [the class or type of felony is left to the determination of individual state legislatures].

Section 15.

If any provision or application of this Act is held invalid, this invalidity shall not affect other provisions or applications of the Act which can be given effect without the invalid provision or application, and to this end the provisions of this Act are severable.